Actionable Patient Safety Solutions #16: Person & Family Engagement

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Abstract

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Executive Summary Checklist

Person and family engagement – often referred to as “patient” and family engagement or “PFE” – is an underutilized resource and strategy for achieving the goal of zero harm. An effective program to optimally implement and sustain PFE should include the following actionable steps:

* Assess strengths and gaps in your organization’s PFE efforts by using this checklist: Have you...
  
  o Elicited feedback from your senior leadership team, staff, patients and families about PFE efforts?
  
  o Inventoried policies, processes, position descriptions and training programs to determine whether PFE is included?
  
  o Discussed findings and conclusions with leadership, staff and patients to create awareness and lay the groundwork for improvement efforts?

* Deploy a system to implement PFE and monitor progress on improving PFE using this checklist. Did you...
  
  o Develop an infrastructure that brings the patient and family voice systemically into your patient safety improvement work, such as:
    
    ? Appointing persons who identify as patients or patient advocates to your governing body,
    
    ? Establishing patient and family advisory bodies that contribute to organizational safety initiatives,
    
    ? Including patient advocate input into improvement committees or root cause analysis teams, and/or
    
    ? Establishing a functional area within your organization whose role and accountability is to engage patients and families?
  
  o Select measures that will allow you to see whether processes and patient safety outcomes are changing?
  
  o Ensure systems are in place so that needed data can be collected and shared?
  
  o Compile results in a format that is easy to understand and monitor?
  
  o Share results with staff, senior leadership, board, community and public?


The Performance Gap

Despite widespread recognition of patient safety as a public health issue since at least 1999, preventable patient harm still occurs. Estimates suggest that the problem may be getting worse not better, although arguably the larger and more alarming estimates now are a product of more effective measurement. For
example, deaths due to medical error in United States hospitals were estimated at 180,000 annually by the landmark Harvard Medical Practice Study in 1984 (Leape, 1995). New research in 2016 suggest that U.S. hospital deaths attributed to medical error are 250,000, making it the 3rd largest cause of preventable death. Existing research or public health data still lacks the ability to reliably estimate preventable harm due to missed, wrong or miscommunicated diagnoses. And data on harm due to medical error in non-acute care settings are still just guesses.

Whatever the estimates the challenge before us is huge and touches millions of people worldwide.

The promising news is that collaborative efforts among healthcare provider organizations, thought leaders and policymaking bodies, payors positioned to incentivize achievement of expected outcomes, innovators and researchers, educators, nonprofit/non-governmental advocacy groups, product makers and activated people who use healthcare can make a difference. Through focused attention and aligned efforts in the United States driven by the Centers for Medicare and Medicaid Services (CMS), measureable patient harm was reduced by 21% between 2010 and 2015, resulting in 125,000 few deaths, 3 million fewer injuries and $28 billion in saved costs. At the local level, collaboration between the public health sector, hospitals and outcomes improvement experts reduced hospital readmissions by 7,000 in Minnesota between 2011 and 2013, enabling patients in Minnesota to spend 28,120 nights sleeping in their own beds instead of the hospital, and helping reduce healthcare costs by more than $55 million.

PFE is an underused “natural resource” for improving the safety of care. Users of healthcare and their family members play substantial roles in managing care and often see and learn things that care providers and researchers miss. If their observations, insights and lessons learned are overlooked in safety improvement, the organization loses important opportunities to prevent harm. In a 2013 editorial, then Health Affairs Editor Susan Dentzer recognized the value of PFE in characterizing it as the “blockbuster drug” of the 21st Century, observing:

Even in an age of hype, calling something “the blockbuster drug of the century” grabs our attention. In this case, the “drug” is actually a concept–patient activation and engagement–that should have formed the heart of health care all along.

Ample evidence has accumulated demonstrating that patients who are actively engaged partners in managing their own chronic healthcare conditions achieve measurably better outcomes. Moreover, persons who use care or manage its use for loved ones are typically highly motivated to partner with their professional and organizational care providers to improve safety. Their experiences bring an urgency to the patient safety movement that propels action by generating empathy – they engage our hearts as well as our minds and hands. In 2006 the World Health Organization captured this urgent offer to partner in the London Declaration of its Patients for Patient Safety group, a core component of its Global Patient Safety Programme:

Growing excitement over the potential of PFE for measurably reducing harm and improving outcomes has generated multiple white papers, frameworks and toolkits designed to engage users of care beyond partnering their own care – notably, as subject matter experts in safety/quality improvement, organizational governance and policymaking. Hospitals, healthcare systems, and ambulatory clinics that have engaged their users of care in improvement work and at the governance level report significant change in growing and sustaining a culture of safety.

The leading framework for PFE was published by Carman and colleagues in 2013, and outlines opportunities for engagement at three levels: (i) Direct Care, (ii) Organizational Design & Governance (applies to health-
Other PFE Frameworks worthy of consideration include:

* Health Information and Management Systems Society, Patient Engagement Framework
* American Hospital Association, Engaging Health Care Users: A Framework for Healthy Individuals and Communities
* FasterCures Patient Perspective Value Framework
Guided by the Carman framework, in 2013 the United States Centers for Medicaid and Medicare Services (CMS) deployed five PFE metrics in a nationwide effort to reduce ten Hospital Acquired Conditions (HACs) as an integral part of its Partnership for Patients campaign. The five hospital-based PFE metrics are expanded upon in the Practice Plan of this Actionable Patient Safety Solutions (APSS). Verified results to date show that hospitals with robust person and family engagement achieved greater reduction in HAC frequency and did so at a faster rate. Based on these initial results, in 2015, six PFE metrics were deployed by CMS in the ambulatory care sector as part of its Transforming Clinical Practice Initiative. The six ambulatory care-based metrics are explained in detail in the Practice Plan of this APSS.

Research and evidence continues to accumulate for the impact of PFE for achieving zero harm, prompting CMS to incorporate PFE into its overall Quality Strategy in 2016. Many hospitals and healthcare systems that have prioritized patient safety are building patient and family advisory councils (PFACs) or other infrastructure that embed PFE. However, many hospitals and clinical practices have yet to incorporate robust PFE into their patient safety programs.

System improvement and patient advocates also underscore the importance of education about PFE in multiple settings, including professional education in medicine, nursing, pharmacy and other healthcare fields. General education about using healthcare safely also is being advocated, in primary or secondary school curricula as well as libraries, online forums or other venues for adult education. All educational efforts should address the needs of vulnerable populations, including those with low literacy or health literacy as well as those with disabilities, cognitive or mental health challenges, limited access to or inability to afford healthcare services, and limited access to or inability to use information technology.
Leadership Plan

To successfully engage patients and families in safety at the point of care and in safety improvement work, a healthcare organization must commit to and invest in a culture of safety and transparency. This begins with and is dependent upon governance and executive leadership that also is committed to and engaged in achieving zero harm. A robust PFE program can help organizational leaders both build and sustain the culture of safety. For these reasons, the Leadership Plan for PFE incorporates and builds on the Culture of Safety Leadership Plan set forth in APSS #1.

Leadership Plan for Culture of Safety (incorporated from APSS #1):

* Hospital governance and senior administrative leadership must commit to becoming aware of this major performance gap in their own organizations. Senior leaders cannot merely be “on board” with patient safety—they must own it.

* Hospital boards must focus on safety and quality, not just finances and strategy. Research demonstrates that patient outcomes suffer when boards do not make safety a top priority.

* Hospital governance, senior administrative leadership, and clinical/safety leadership must close their own performance gap by implementing a proactive, comprehensive approach to addressing the culture of safety.

* Healthcare leadership (clinical/safety) must reinforce their commitment by taking an active role in championing process improvement; giving their time, attention and focus; removing barriers, and providing necessary resources.

* Healthcare Leadership must demonstrate their commitment and support by shaping a vision of the future, providing clearly defined goals, supporting staff as they work through improvement initiatives, measuring results, and communicating progress towards goals.

* There are many types of leaders within a healthcare organization, and in order for process improvement to truly be successful, leadership commitment and action are required at all levels. The Board, senior leadership, physicians, pharmacy and nurse directors, managers, unit leaders and patient advocates all have important roles and need to be engaged in specific behaviors that support staff to provide safer care.

* Safety culture and performance must be valued and reflected in compensation plans so that leaders have direct personal accountability for results.

Additional Leadership Plan Components for PFE:

* Ensure your organization has a clear definition of PFE.

* Discuss PFE with your senior leadership team so that they understand that it matters to you and the organization.

* Elicit input from your board, your staff and representative patients and families about what your organization will look like if it is successfully engaging patients and families.

* Make improving PFE an organizational goal.

* Establish infrastructure in your organization that creates pathways for PFE input in safety improvement work.
Allocate time in meetings with senior leadership, staff and the board to hear and tell stories about engagement success and shortcomings.

**Practice Plan**

Healthcare organizations should consider using the Carman framework or an alternative framework (see list above in the Performance Gap section) to implement a PFE program that engages patients or their family members at two levels:

I. Avoiding preventable harm in their own care [Level: Direct Care], and

II. Serving as organizational advisors on operational improvement work or as contributors to Board of Governors oversight on patient safety [Level: Organizational Design and Governance].

Healthcare organizations should consider establishing a PFE infrastructure that aligns with and advances the innovation currently being driven by CMS. In hospitals and multi-site systems, this includes deploying a five part PFE practice plan:

1. Use of a checklist during the patient discharge process for all elective hospital stays to ensure reliable transmission of discharge instructions [Level: Direct Care];

2. Performance of safety huddles and nurse shift changes at the patient bedside including active patient participation in the process [Level: Direct Care];

3. Assignment of PFE responsibility as the function of a hospital organizational unit or the job description of at least one hospital employee [Level: Organization Design & Governance];

4. Establishment of a Patient and Family Advisory Council or equivalent structure to include patient input into hospital safety and quality improvement work [Level: Organization Design & Governance];

5. Appointment a person who identifies primarily as a patient or family member to the hospital Board of Governors or a Board-level committee with oversight of safety and quality [Level: Organization Design & Governance].

In non-acute care clinics or other ambulatory care delivery sites, a six part PFE practice plan should be considered.

1. Use of a tool to assess patient readiness to be “activated” as a partner in the patient’s own care [Level: Direct Care];

2. Use of a tool to assess a patient’s degree of health literacy [Level: Direct Care];

3. Use of a tool to support shared decision-making between patients and their providers;

4. Establishment of a process to support medication use [Level: Direct Care];

5. Use of a technological platform to communicate with or provide information to patients [Level: Direct Care]; and

6. Establishing a Patient and Family Advisory Council or equivalent infrastructure to include patient input into safety improvement work [Level: Organization Design & Governance] [Level: Organization Design & Governance].
At the Organizational Design & Governance level, healthcare organizations should consider engaging users of care in improvement efforts and measure progress in one or more of the following areas:

* Adverse Drug Events
* Catheter-Associated Urinary Tract Infections
* Central Line Associated Blood Stream Infections
* Injuries from Falls and Immobility
* Obstetrical Adverse Events
* Pressure Ulcers
* Surgical Site Infections
* Venous Thromboembolism
* Reducing Hospital Readmissions
* Clostridium Difficile (c-diff)
* Airway Safety
* Severe Sepsis and Septic Shock
* Hospital Acquired Acute Renal Failure
* Ventilator-Associated Pneumonia
* Effective Management of Critical Test Results
* Iatrogenic Delirium
* Procedural Harm
* Undue Exposure to Radiation
* Failure to Rescue
* Hospital Culture of Safety
* MRSA
* Pain management

**Technology Plan**

*Suggested practices and technologies are limited to those proven to show benefit or are the only known technologies with a particular capability. As other options may exist, please send information on any additional technologies, along with appropriate evidence, to info@patientsafetymovement.org.*

Use of information and communication technology is a particularly fertile area of innovation being used to engage patients. Examples include electronic patient portals, smart phone apps, email and texting pathways and OpenNotes.
OpenNotes is an international movement advocating patient access to all aspects of their electronic health records, including physician notes and diagnostic tests. Supporters believe that providing ready access to notes is transformative in empowering patients, families, and caregivers to feel more in control of their healthcare decisions, and improve the quality and safety of care. Researchers in the OpenNotes community are collaborating closely with health systems, healthcare professionals and millions of patients around the world to understand the effects of fully transparent medical care on communication, engagement, safety, costs, and the overall quality of care.

Many companies are producing technological solutions designed to advance PFE. Healthcare organizations are encouraged to use the HIMSS PFE framework displayed below to track innovation in this space. However, patient advocates also cite the digital divide and urge that PFE implementers be aware that many people are not proficient in the use of information technology or do not have access to it, and take steps to ensure that these patients are not left behind.

Healthcare organization should also consider using their Serious Safety Event reporting system, or any alternate or complementary reporting systems used to track patient safety outcomes.

When possible, healthcare organizations should consider integrating patient complaints, the narrative portions of patient satisfaction surveys or other mechanisms that patients and families use to communicate concerns about patient safety events. Innovations such as MedStar Health’s “We Want to Know” platform specifically designed to prompt complaints and suggestion from users of care, show promising results: Patients in the MedStar system are reporting patient safety events or aspects of events that hospital staff have failed to report.

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**Metrics**

Healthcare Organizations should consider using the metrics deployed by CMS to measure the uptake and impact of PFE.

In the acute care (hospital) sector, the CMS Partnership for Patients metrics are:

1. Hospital has a planning checklist that is discussed with every patient who has a scheduled admission, [Level: Direct Care].
   a. You’ll meet this metric if the hospital uses one of these planning resources:

2. Hospital conducts shift change huddles for staff and does bedside reporting with patients and family members in all feasible cases [Level: Direct Care].
   a. You’ll meet this metric if the hospital uses any of these tools:
      iii. The Family-Centered Rounds Toolkit from the University of Wisconsin–Madison School of Medicine and Public Health; American Family Children’s Hospital; and AHRQ: [http://www.hipexchange.](http://www.hipexchange.)
3. Hospital has a designated individual (or individuals) with leadership responsibility and accountability for PFE, (i.e. open chart policy, PFE trainings, establishment and dissemination of PFE goals) [Level: Organizational Design & Governance].
   a. You’ll meet this metric if the hospital uses one of these resources to develop a PFE liaison:
      i. Staff liaison to patient and family advisory councils and other collaborative endeavors (Institute for Patient- and Family-Centered Care): http://www.ipfcc.org/resources/Staff_Liaison.pdf.

4. Hospital has an active Patient and Family Advisory Council (PFAC) or at least one patient who serves on a patient safety or quality improvement committee or team. [Level: Organizational Design & Governance].
   a. You’ll meet this metric if the hospital uses any of the following guides to develop a PFAC:
      iii. Patient Engagement in Redesigning Care from the University of Wisconsin Health Innovation Program: http://hipxchange.org/PatientEngagement

2. Hospital has at least one or more patients who serve on a Governing and/or Leadership Board and serves as a patient representative [Level: Organizational Design & Governance].
   a. You’ll meet this metric if the hospital uses any of the following guides:

In the ambulatory care sector, the CMS Transforming Clinical Practice Initiative metrics are:
1. Support for Patient and Family Voices [Level: Organizational Design & Governance]: Are there policies, procedures, and actions taken to support patient and family participation in governance or operational decision-making of the practice (Patient and Family Advisory Councils (PFAC), Practice Improvement Teams, Board Representatives, etc.)?

   a. You’ll meet this metric if your clinical practice uses any of the following tools for including the perspective and active voice of the patient and family (Patient Family Advisor) in all aspects of the governance of the practice.


2. PFE Metric 2: Shared Decision-Making [Level: Direct Care]. Does the practice support shared decision-making by training and ensuring that clinical teams integrate patient-identified goals, preferences, outcomes, and concerns into the treatment plan (e.g. those based on the individual’s culture, language, spiritual, social determinants, etc.)?

   a. You’ll meet this metric if your clinical practice is using Patient Reported Outcomes (PROs) and Patient Reported Outcomes Measures (PROMS) or a shared decision-making tool like the ones listed here:

   i. Overview on implementation of PROs and PROMs: https://catalyst.nejm.org/implementing-proms-patient-reported-outcome-measures/ and https://catalyst.nejm.org/shared-decision-making/

   ii. National Institutes of Health inventory of PROMs: http://www.healthmeasures.net/explore-measurement-systems/promis


3. PFE Metric 3: Patient Activation [Level: Direct Care]. Does the practice utilize a tool to assess and measure patient activation?

   a. You’ll meet this metric if your clinical practice is using Patient Activation Measures or other assessments of patient readiness to partner like the ones listed here:


4. PFE Metric 4: Active e-Tool [Level: Direct Care]. Does the practice use an e-tool (patient portal or other e-connectivity technology) that is accessible to both patients and clinicians and that shares information such as test results, medication list, vitals, and other information and patient record data?

a. You’ll meet this metric if the practice uses (and makes available to patients) an e-tool such as OpenNotes that allows patients to access their medical record and have an easy, direct way to communicate with providers. Examples include:

i. OpenNotes, https://www.opennotes.org/.


iv. Patient Engagement Playbook from the office of the National Coordinator for Health Information Technology, https://www.healthit.gov/playbook/pe/

v. AHRQ Health Information toolkit, https://healthit.ahrq.gov/health-it-tools-and-resources

5. PFE Metric 5: Health Literacy Survey [Level: Direct Care]. Is a health literacy patient survey being used by the practice (e.g., CAHPS Health Literacy Item Set)?

a. You’ll meet this metric if your practice use tools like the ones listed below to systematically address health literacy through universal precautions and assessing how well patients understand information provided to help them manage their health.


6. PFE Metric 6: Medication Management [Level: Direct Care]. Does the clinical team work with the patient and family to support their patient/caregiver management of medications?

a. You’ll meet this metric if there is a systematic, standard method in place to evaluate and support patients and their caregivers in medication self-management. There are many toolkits including these:


Additional Resources

1. PFE resources are easily accessed yet need to be encouraged along the continuum of care.

a. You can encourage PFE by providing updated resources and conversing with patients and family members about how they may utilize the information. The following resources have been identified as useful by patients and/or their family members.


iii. EngagedPatients.org, Engaged Patients is a national campaign under the guidance of the Empowered Patient Coalition nonprofit with the vision that all patients and their loved ones have free access to the tools and the resources they need to be fully informed and participating members of their health care teams., http://engagedpatients.org/wp-content/uploads/2014/06/epc_patient_journal.pdf

iv. Minnesota Alliance for Patient Safety, You: Your Own Best Medicine, http://ownbestmedicine.mn


viii. Motivational Interviewing tools, http://www.practiceadvisor.org/Modules/improving-clinical-care/motivational-interviewing/login?ReturnUrl=/Modules/improving-clinical-care/motivational-interviewing [Note: Access requires registration, but it is grant supported so there is no cost to users].

2. Education: Everyone from youth to the most experienced clinician has an opportunity to improve healthcare safety through increased PFE.

a. You can contribute by educating others within your area of influence.


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References

